

CHAPTER 3:

Collect Diversity Data



Introduction

Gathering data about race, ethnicity and language (REL) is essential. In fact, data collection is where the cultural competence cycle begins and ends. Data begins the cycle by helping you better understand and serve clients. It closes the cycle by providing a reflection of progress and areas for improvement. Collecting REL data can not only allow your agency to meet state and federal requirements, but it can also have a powerful impact on your cultural competence skills.

Chapter 3 presents tools to assist agencies in the process of collecting diversity data. It begins with an overview of benefits and requirements. Then, it presents a sample process and tools to help agencies collect data, update systems and identify affordable resources.





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CLAS Standards Covered

Standard 10:

- Collect data on client race, ethnicity and language
- Integrate CLAS data into information systems and client records
- Update data periodically

Standard 11:

- Conduct a needs assessment to identify the needs of populations suffering health disparities
- Maintain current demographic, cultural, epidemiological profiles of the community.

Standard 14:

- Make information about CLAS initiatives and successes available to the public.
- Provide public notice about available information

Why Collect Race, Ethnicity and Language Data?

Meet State and Federal Reporting Requirements

State and federal policies support race, ethnicity and language data collection. In fact, new federal policies encourage more detailed data collection. In Massachusetts, for example, all acute care hospitals are required to collect and report detailed race and ethnicity demographic information.¹

Set the Foundation for Cultural Competence

Understanding clients and their needs is the starting point for cultural competence. Having REL data is often a prerequisite for meeting other CLAS requirements, like offering interpreter services, budgeting, planning and self-assessments.

Prevent and Eliminate Health Disparities

Regularly reviewing updated demographic data is key to identifying, preventing and eliminating health disparities. A 2002 study by the Institute of Medicine notes that certain biases and stereotypes are “...invisible to institutions and providers unless they constantly gather and analyze data about treatments according to the race and ethnicity of the clients.”¹ Reviewing data about populations served can help you “see” invisible biases, identify patterns of discrimination and correct them.

Become More Responsive to Cultural Preferences

Staying attentive to data can help agencies become more aware and responsive to cultural preferences and demographic changes. For example, understanding what language clients prefer to be addressed in can help improve communication.

Tailor Services to Diverse Needs

As you gain insights into cultural issues related to care-seeking and use of services, you can better plan for new services and policies, and target your efforts. Data can also help you identify translation and interpretation needs and refine educational materials.

Use Resources Cost Effectively

Having the right data facilitates planning your budget according to real needs and preventing waste.

Become More Competitive

Collecting race, ethnicity and language data can help your agency become more competitive in two ways. First, it enables agencies to attract more clients through services that meet client needs. Second, having updated REL data is documented proof of efforts to meet CLAS for state Requests for Responses (RFRs) and contracts.

Data collected by Massachusetts health institutions are used to:

- Identify differences in health use and outcomes for clients of different races and ethnicities
- Develop programs to address health disparities
- Target programs and services to those in need
- Develop health care policy
- Assist with public health studies
- Identify illnesses that are more prevalent in some ethnic groups and improve treatment protocols for them

Source: Massachusetts Hospital Association (2006)²

¹ See state regulation 114.1 CMR 17.00, adopted July 2006 and updated September 2006.

Step 1. Identify Diverse Populations

Consult a Variety of Sources

When they think of demographic data, most people think of U.S. Census or official state numbers. These are good sources to start with. However, with a constantly changing population, these data alone may not be enough to give a full picture.

Often, gaining a detailed picture requires combining data from a variety of sources.

Work with Community Partners

Looking to the community can add dimension to data. At the community level, you can find information to

make numbers come to life. Knowing, for example, how many African immigrants are in your service area is important. Knowing about their health beliefs and traditions adds a new level of depth.

The best sources of community data are often members of the community itself. Working with key members of the community can help anticipate trends. Key partners can serve as **cultural brokers** (see Glossary), who can help your agency gain important cultural insights. Local churches can also be good places to get the pulse of minority populations. For example, one provider sought out expertise on Mayan-Quiche women by visiting a local church that attracted many of her clients.

“Schools will regularly survey students to find out what languages they speak.

Looking at these surveys has given us a good sense of what languages the families in our neighborhoods are speaking at home, and what countries they come from.”

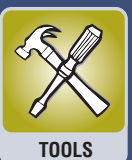
– A Boston public health professional



Data Collection Sources

Consider using a variety of sources, including:

- Community sources
Massachusetts Mutual Assistance Associations, faith-based organizations, professional organizations
- Local hospital utilization data of primary/preferred language of clients
- Office of Refugee and Immigrant Health <http://www.mass.gov/dph/orih/orih.htm>
- Massachusetts Immigrant Refugee Advocacy Coalition (MIRA) <http://www.miracoalition.org>
- Massachusetts Department of Education and First Language Is Not English (FLNE) and Limited English Proficiency (LEP) surveys (analyzed by MDPH) <http://www.mass.gov/dph/healthequity>
- Municipal Boards of Health
- Massachusetts Division of Medical Assistance data
- Massachusetts Community Health Information Profile (MassCHIP) <http://masschip.state.ma.us/>
- U.S. Census data of your service area <http://www.census.gov>



Tool 3.4: REL Data Sources Chapter 2: Build Community Partnerships

Step 2. Develop a Standard Process

While data collection may vary from one public health agency to another, the purpose of collecting the information is the same: to identify disparities and barriers to access, monitor services, identify and prevent discrimination, and improve client care.

Define an Overall Approach

There is no one-size-fits-all way to collect data. There are, however, principles that can make for a smoother process. This chapter compiles helpful information from the Massachusetts Department of Public Health, the Massachusetts Hospital Association, the Cambridge Health Alliance and the Health Research and Evaluation Trust.³

This information can help you develop an approach that meets the needs of your agency, that uses consistent processes, and incorporates

REL data collection into your daily operations. This will ensure you have information available when you need it, for example, when you are submitting paperwork for a contract, planning budgets, or developing new programs.

Develop a Standard Process

A consistent, step-by-step approach will allow you to gather correct information, organize it and analyze it according to your needs. The goal is to develop a process that is simple enough that everyone who is involved can consistently do his or her part.

As you plan for data collection, ask: When will you collect the data? Who will collect the data? What will you tell clients? How will you address confidentiality? How will you collect the data? What information will you collect? What tools will you use to collect and store information? And, how will you train staff?





A Process for Collecting REL Data

When?	Ask for race, ethnicity and language data early on—ideally, during admission or client registration.
Who?	Admissions or reception staff should collect data.
What will you tell clients?	Address concerns up front and clearly. Before obtaining information, develop a script to tell clients: <ul style="list-style-type: none">■ This information is important (explain why)■ We will use it to improve care and services and to prevent discrimination■ Your information will be kept confidential
How?	Clients self-report—select their own race, ethnicity and language.
What information will you collect?	Start with the MDPH categories (see Tool 3.2), and add your own according to needs.
Tools to collect and store data	Use standard collection instruments. Store data in a standard electronic format.
Training	Provide ongoing data training and evaluation to staff.

Adapted from the Health Research and Evaluation Trust Health Disparities Toolkit ³

When should you ask for race, ethnicity and language data?

The goal is to get the information early in your encounter with a client. Ideally, ask prior to an appointment or during phone registration. If you can't get the information at that point, try to do it as soon as possible after an appointment.

Who will collect client information?

This will depend on the size and needs of your organization. Because they are the first to see clients, it helps to have front line staff (like receptionists) collect the information.

What will you tell clients?

Many clients, especially those of different backgrounds, may be concerned when you ask questions about their race or ethnicity. Be sensitive to concerns and explain why you are collecting data and how you will use it.

Research shows that once they understand the purpose of questions, most clients are happy to cooperate. Recent surveys conducted in Massachusetts show that most patients believe it is important for hospitals and clinics to collect information from patients about their racial and ethnic backgrounds.⁶

Before you ask for any information, tell clients:

- Data will NOT be used to discriminate against clients.
- Data WILL be used to identify inconsistencies in service.
- Data WILL be used to ensure that all clients receive the highest quality care and services.
- Information WILL be kept confidential and participation is voluntary.

How will you address confidentiality?



Is Collecting Race, Ethnicity and Language Data Legal?

While specific guidelinesⁱⁱ regulate the collection of race, ethnicity and language data, it is fully legal. Federal civil rights (Title VI) law and malpractice liability laws favor the collection and analysis of race and ethnicity data as a way to⁴:

- Improve the quality of health programs and services
- Analyze how well health providers meet the needs of diverse populations
- Take affirmative steps to overcome and prevent discrimination
- Demonstrate how organizations prevent and remedy discrimination

What About HIPAA and Other Privacy Laws?

The Health Insurance Portability and Accountability Act (HIPAA) is concerned primarily with disclosure—what happens with client information once it has been collected. Having information about clients' racial and ethnic background requires sensitive and responsible handling. Agencies must ensure that information is kept confidential and is never used to discriminate.

How will you collect information?

The Massachusetts Department of Public Health recommends using the “client self-report” method. Client self-report means each client has the opportunity to choose his or her race and ethnicity from several categories. Self-reporting is the most accurate source of information. Because it reflects how clients describe themselves, it prevents guesswork by others.



Massachusetts Information Collection Requirements

The Massachusetts Department of Public Health and its contracted agencies have authorization to collect data for public health surveillance, planning, research, program development and evaluation, setting strategic priorities, evaluating the impact of outreach and messages on different populations, evaluating the efficacy of programs, and addressing health disparities.

Massachusetts guidelinesⁱⁱ require agencies to ensure that REL data will be kept confidential and that it will not be used to discriminate.

If agencies are to collect data, including race, cultural origin and ethnicity, for purposes other than those authorized for MDPH, agencies must obtain permission from proper state authorities and must offer proof that such information will be used in good faith and for a proper purpose. Agencies must detail the purposes for additional use of the data.

ⁱⁱ Massachusetts Executive Order 478: Order Regarding Non-Discrimination, Diversity, Equal Opportunity and Affirmative Action, Section 6



See **Appendix B:**
Overview of Laws



See **Tool 3.1:**
**Explaining the Data
Collection Process
to Clients**

Use an introductory statement explaining why you are collecting information and how it will be used. Offer clients a minimum of five race categories plus the Hispanic/Latino ethnicity category. Clients should be able to choose more than one category. They should also have the option not to answer if they so choose (“declined/unavailable” option).

What information will you collect?

Data categories, simply put, are the kinds of information asked for. Age, race, gender and income are examples of data categories. Being consistent in the kinds of data collected makes it easier to compare and analyze those data in the future.

It helps to put this in a standard script. You can find a sample script in Tool 3.1.

As you select data categories, use the Office of Management Budget (OMB) and Massachusetts Department of Public Health (MDPH) categories as a starting point (see Tool 3.2). While the OMB guidelines require only the collection of five race categories plus the Hispanic/Latino ethnicity categories, the MDPH recommends going into greater detail.

Cover the basics: race, ethnicity and language. Then, add other categories (such as gender, client satisfaction levels, age, income and education) for more detail. Collecting information on broad race groups helps uncover disparities. Collecting detailed ethnicity data is crucial for targeting culturally appropriate services. See the chart on the next page for category ideas.

“Gathering data about our clients’ ethnic backgrounds has been really important for us. We have a lot of clients from African countries that are of the same race but have very different ethnicities. If you only ask for race and don’t ask for ethnicity, you don’t get the full picture.”

– A Worcester public health professional



Office of Civil Rights Data Collection Guidelines

The U.S. Department of Health and Human Services’ (HHS) Office of Civil Rights (OCR) Title VI guidelines⁵ require that the following information be included in the file of each client:

- Preferred spoken language
- Preferred written language
- Whether or not the client was informed of the right to interpreter services
- How this information was conveyed
- Whether the client accepted or declined this service
- If accepted, how this service was provided



Massachusetts Department of Public Health Recommendations on Race, Ethnicity and Data Collection⁶

- Encourage clients to self-report in the registration process.
- Collect Hispanic ancestry and race categories consistent with federal OMB standards.
- Expand data collection to include detailed ethnicity data.
- Collect language data consistent with language guidance issued by the U.S. Department of Health and Human Services. <http://www.hhs.gov/ocr/lep>
- Allow people to identify as many categories as they wish to describe their complete race and ethnicity heritage.

Why REL?

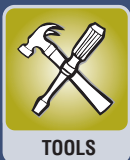
Race. Ethnicity. Language. These three categories are the ones to remember when collecting client data. Why collect all three? To obtain a three-dimensional view of your clients. For example, a client whose race is black could be American, Haitian, or Nigerian. You need more information, like nationality, to better understand the client's background.

And language? A client's primary language informs you of how he or she prefers to communicate and when to offer interpreter services, forms and materials in a language other than English. And, it is required by the Office of Civil Rights.

Race is defined as the groups that you identify with as having similar physical characteristics or similar social and geographic origins.

Ethnicity refers to your background, heritage, culture, ancestry, or sometimes the country where you or your family were born.

Sample categories for data collection:	
Client Data <ul style="list-style-type: none">• Race• Ethnicity• Nationality• Preferred spoken / written language• Age• Gender• Sexual orientation / gender identity• Income• Education• Informed of right to interpreter services• Use of interpreter services• Treatment history• Medical history• Outcome data (service type, utilization, length of stay)• Client satisfaction	Staff Data <ul style="list-style-type: none">• Race• Ethnicity• Nationality• Primary/preferred language• Gender• Records of cultural competency training participation and evaluations
Sources: Boston Public Health Commission Hospital Working Group Report, Technical Assistance Partnership for Child and Mental Health ⁷	



See:

Tool 3.2: MDPH Detailed Ethnicity Categories

Tool 3.3: MDPH Preferred Data Collection Instrument

What tools and systems will you use to collect and store data?

To ensure the accuracy of data collection, it helps to use instruments (client forms, surveys, etc.) and information systems that conform to new guidelines.

In its HRET Disparities Toolkit⁸, the Health Research Education Trust suggests that data collection instruments should include:

- A rationale for why the client is being asked to provide race, ethnicity and language information
- A script for staff to use each time so that they ask questions in a uniform way
- A method allowing clients to self-identify their race, ethnicity and language
- A standardized approach to “fit” your categories with OMB categories for analytical and reporting purposes
- Assurances that the data will be held confidential and that a limited number of people will have access to the data, and a mechanism to guarantee this claim

How will you train staff?

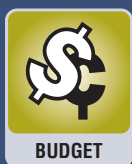
Asking for race, ethnicity and language information in an institutional setting can be uncomfortable. Staff must be trained to ask these sensitive questions. Using a standard process, and practice, can help ease the discomfort of asking these questions.

After pilot testing its data collection programs, the Massachusetts Department of Public Health reported that “training data collectors makes them much more comfortable asking these sensitive questions since they understand the importance of the information, how it will be used, how to respond to questions, and how to overcome uncertainty and resistance.”⁹

Use formal opportunities (such as new employee training, staff meetings and evaluations) as well as informal opportunities to train staff on the use of REL data collection. The Massachusetts Department of Public Health, the City of Boston and Massachusetts General Hospital offer training materials specifically for race, ethnicity and language data collection in health care settings.

“Updating our data collection systems was a major undertaking. We had to update our data entry system, records and forms, translate forms into different languages, and train employees on how to use the new forms and systems. It was a big project. But it helps tremendously. Now we can print and compare data on a moment’s notice. It gives us a reflection of where we really are.”

– A Worcester public health professional



BUDGET

Updating Data Collection Systems

Ensuring data collection systems capture new categories may be the most challenging part of updating your data collection methods. It requires time and training. But it isn’t impossible. See Tool 3.5 for more.



TOOLS

See:

Tool 3.5: Low Cost Data Collection Tools

Tool 3.6: Data Resources

Step 3: Integrate Race, Ethnicity and Language Data Collection into Your Framework

Making data collection a part of daily operations is the best way to make sure it is collected consistently. The goal is to make it a habit, a standard part of client registration. If staff have to go out of their way to collect the information, they are less likely to do it.

Incorporate REL into Existing Forms, Processes and Systems

Think of ways to make race, ethnicity and language data collection part of day-to-day operations. For example, instead of creating a new form specifically for REL data, consider incorporating new categories into your existing forms. Also, make sure you ask clients to report their race, ethnicity and language preferences as part of the standard registration process. As employees become familiar with new systems, use reminders, like flags or check boxes in forms.

Ensure Records “Fit” with MDPH and Other Reporting Systems

If you are adding REL categories and updating your data collection systems, keep in mind how these will appear in reports and how they will integrate with other reporting systems.

Step 4: Assess Needs and Areas for Improvement

Out of context, data have no value. For the purposes of cultural competence, REL data should be used to offer a clear sense of who your clients are and how well your agency meets their diverse needs. How you collect data is important. Even more important is how you use data once you have it.

Evaluate Client Satisfaction Levels

In addition to collecting demographic data, CLAS guidelines recommend evaluating client satisfaction. This can be done through surveys, focus groups and reports from staff working directly with diverse populations (e.g. interpreters, reception staff).

Benchmark

Once you begin collecting data on a regular basis, CLAS guidelines encourage using those data for evaluations, annual reports and benchmarking. Use concrete data to evaluate performance and identify areas to improve. Make plans accordingly. *See Chapter 4 for more information on benchmarking.*

How you collect data is important. How you use data once you have it is even more important.



Field Lessons: Tracking Client Progress and Language in a Single Form

To streamline language data collection, a public health agency in Central Massachusetts tracks client progress and use of interpreter services in a single form. The client progress note has a box where providers can check off “Were interpreter services used? Interpreter used or refused?”

Compare Client Health Across Race, Ethnicity and Language

Having information broken down by race, ethnicity and language allows you to compare health outcomes by these categories. You can then identify gaps and problem areas, and apply resources to improve services.

Identify and Prevent Health Disparities and Discrimination Trends

Comparing health information by racial and ethnic background allows agencies to identify health disparities and potential areas of discrimination.

Budget and Plan for Programs and Services According to Needs

Developing new programs takes much time and planning. Updated, correct data can help you allocate funds for programs that meet real needs.

Plan for Language Services

Having information ahead of time can help you avoid scrambling to find an interpreter. If you anticipate needs with accurate data, you can plan ahead for language needs.

Hire Staff that Are Reflective of Your Clients

Knowing whom you serve can help you identify cultural competence skills needed in employees. Updated data can help you determine how well staff diversity and skills match the diversity of clients, and can help you improve that diversity.

Step 5: Share Diversity Data with Staff and Community

As part of a collaborative effort to end health disparities and share successes, the CLAS standards recommend sharing information. You can accomplish this through social marketing, newsletters, client information materials, meetings, reports, brochures, presentations and informal exchanges with community partners. For more details on this topic, see Chapter 2.

While sharing information can have a positive impact, it is crucial to maintain client confidentiality at all times. Data shared with the community and other agencies should contain no personally identifiable information. Reports should reflect overall trends and patterns, and should never contain any information that can be linked to individuals.

As part of a collaborative effort to tend health disparities, the CLAS standards recommend that you share cultural competence knowledge.



See:
**Chapter 2: Build
Community
Partnerships**

Conclusion

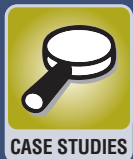
Following new data collection guidelines requires dedicated efforts and investment. But the benefits far outweigh the costs. If your program is committed to cultural competence, data can be your ally. Gathering information about your clients' race, ethnicity and language should be the starting point for offering client-centered care.

Benefits of Race, Ethnicity, and Language Data Collection

Having updated race, ethnicity and language data can help you:

- Understand the racial and ethnic background of clients
- Determine how well your staff diversity “matches” client diversity
- Compare health outcomes data across race, ethnicity and language
- Identify health disparities and discrimination trends
- Adapt services to health and cultural needs
- Incorporate valuable information into staff training and evaluations
- Identify areas to improve and develop strategies to improve
- Determine what language services are needed
- Plan for programs and services according to reported needs
- Distribute funds according to needs
- Meet RFR and contract requirements





Case Study 3: Using Data to Develop Relevant Programming

The Agency: Cambridge Prevention Coalition
Services: Community prevention activities, education, training and technical assistance services, substance abuse community forums
Client Population: White (48%), Hispanic (30%), Cape Verdean (10%), Portuguese (6%), African-American (< 4%), Asian (< 1%)

Background

The Cambridge Prevention Coalition (the Coalition) is a community-based coalition linking substance abuse prevention to a range of health promotion initiatives. The Coalition seeks to promote community health and wellness through the reduction and prevention of substance abuse. The core of the Coalition's effort is based on coordinating and promoting collaborative community prevention efforts.

Challenge

Upon receiving the Mass Call 2 Grant—a grant awarded to programs throughout Massachusetts with the purpose of reducing opiate overdoses in the community—the Coalition was given the challenge to assess services to better serve and understand their target population: opiate users in the city of Cambridge.

Approach

Finding Clues in Existing Data Sources

Gisela Rots, Director of the Coalition, and her team began the process by consulting a variety of data sources, including: MassCHIP; Drug Awareness Warning Network (DAWN) member hospital data; Pro-Ambulance data; Cambridge Police Department drug arrest and drug incident data; and Cambridge Cares About AIDS (Cambridge Cares) data collected as part of their needle exchange program.

Collecting their Own Data

Looking at existing data was only the beginning for the Coalition. The team continued their research by collecting qualitative data with interviews, surveys, and focus groups with treatment providers, opiate users and their families.

Interviews

The Coalition conducted one-on-one interviews with providers, homeless service programs, emergency room doctors, addiction specialists and treatment providers in the city of Cambridge.

Surveys

Rots and her team worked closely with Cambridge Cares, providers and community partners to develop, test, and distribute a survey for opiate users.

Focus Groups

To complete the picture, the Coalition spoke with families of users, both in focus groups and one-on-one interviews. This offered family members an opportunity to tell their stories and discuss factors contributing to opiate use. It also provided a forum to share ideas and suggestions for improvements.

“It’s important to look at cultural competence with a wide lens. The usual demographic data is important, but I think we need to go beyond that. Collecting data is broader than just gathering racial and linguistic information—it’s about getting to the true culture and motivations of the people.”

– Gisela Rots,
Director,
Cambridge
Prevention
Coalition

Case Study 3: Using Data to Develop Relevant Programming (cont.)

Going Beyond Demographics

The Coalition's research explored key issues around opiate overdose, prevention and contributing factors. One very interesting point, according to Rots, was asking opiate users what helped prevent future opiate overdoses. "Most of the respondents gave very similar responses. In fact, their suggestions alluded to a program that was already being funded. This was very positive because it confirmed that our money was going into a program that mattered to our clients," Rots said.

Identifying Targets

As the Coalition grouped and organized data from different sources, they were able to confirm their target population for the opiate prevention program.

Using Data to Focus on the Right Population

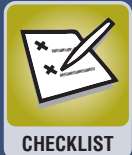
According to Rots, "having updated data about our target population has offered us clear benefits. The information we have collected gives us a focus—it allows us to confidently focus on a population and **know that we are reaching out to the right population**. It has also added legitimacy to our program in the eyes of the community."

Bringing Clients to the Table to Stay Informed

Gathering data in the community has offered a number of unexpected benefits for the Coalition. In particular, connections were made with opiate users' family members, who have since become involved as advisory members. "It's so much more interesting to have them at the table," Rots says. "Besides getting buy-in from clients and their families, it just makes the work so much more interesting."

"It's so important to understand your target population. Without data, you won't be able to provide services that are accepted by your population—or you may provide the wrong services. Without data, you may be spending your funds to create programs that are irrelevant."

– Gisela Rots,
Director,
Cambridge
Prevention
Coalition



Chapter 3 Checklist: Collect Diversity Data

This checklist includes suggested ways for your agency to become more culturally competent. All agencies may not be able to accomplish these right away. Some may be goals for the future. These measures describe specific ways to document CLAS efforts when responding to Requests for Responses (RFRs) and contracts.

Step 1. Identify Populations Served

- Updated demographic data are collected regularly from a variety of state and federal sources, community-based organizations, refugee assistance services, FLNE surveys, MassCHIP, etc.

Step 2. Develop a Standard Process

- A standardized process exists for data collection, specifying who collects data, when data are collected, what categories are used, where data are stored, how client concerns are addressed, and how staff are trained.
- Forms explain the purpose and intended use of data, assure that data will be kept confidential and allow clients to self-identify REL.
- A data collection script exists detailing how staff can ask questions about race, ethnicity and language in a uniform way.
- Data categories and indicators are consistent with federal OMB standards and MDPH-preferred race, ethnicity and language categories.
- Staff receive training on REL data collection and use of electronic systems.

Step 3. Integrate REL Data Collection into Frameworks

- REL data collection is integrated into regular client procedures (e.g., intake).
- Electronic client records contain race, ethnicity and language data.
- Client forms include questions on race, ethnicity, language, interpreter services.

Step 4. Assess Needs and Areas for Improvement

- Client satisfaction surveys and focus groups are conducted.
- Annual reviews and reports incorporate race, ethnicity and language data.
- Data are compared across race, ethnicity and language to identify trends of disparities or discrimination.
- A plan exists to track progress in decreasing disparities identified by clinical indicators, client satisfaction and quality improvement activities.

Step 5. Share Appropriate Data

- Reports of relevant data are shared at staff, board, planning and evaluation meetings.
- Appropriate data are shared with other health agencies, community organizations and the public through printed materials, e-mail, social marketing initiatives, presentations, meetings, staff meetings, and other dissemination methods.
- Notices of available information are made to the public.

Chapter 3 References

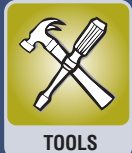
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CHAPTER 3: Collect Diversity Data

Tools



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- 3.5: Low-Cost Data Collection Tools
- 3.6: Resources



Tool 3.1: Explaining the Data Collection Process to Clients

Asking clients for race and ethnicity information can be challenging. Training staff to use a standard process when asking for race, ethnicity and language data can help. The following script can serve as a model.

Before asking for any information, tell clients:

- We are collecting race and ethnicity data for all clients.
- We need this information to know more about your culture and language to improve the care we offer all clients.
- This information will be kept private and only be used to meet the needs of all clients we serve.
- We will NOT use this information to discriminate against clients.

A sample introductory statement could look like the following:

“We want to make sure that all our clients get the best care we can offer regardless of their race or ethnic background. We would like you to tell us your race and ethnic background so that we can review the services all clients receive and make sure everyone gets the highest quality of care. The collection of this information is confidential and voluntary. It will never be used to discriminate or affect the way we provide services.”

If a client asks, “Why?” Explain:

- We are collecting this information from all clients. This will help us to see differences in health among different populations.
- We can reduce those differences by making sure that all clients receive the same quality of care.
- Collecting this information is legal according to federal and state laws. There are new state regulations that require Massachusetts health service providers to collect this information. We have obtained permission from state officials to collect this information.
- This information will only be used to meet the needs of clients.
- We will not share this information with Immigration Services.

If a client asks about privacy, tell him or her:

- Your privacy is protected.
- Would you like a copy of our privacy statement?

Tool 3.1: Explaining the Data Collection Process to Clients (cont.)

If a client asks, “What is ethnicity?” Use the following definition.

Ethnicity refers to your background, heritage, culture, ancestry or sometimes the country where you were born. You can tell me more than one.

If a client responds, “I’m multiethnic,” explain:

We can record as many categories as you need to describe yourself. Please tell me all of your ethnicities.

If the client cannot describe his or her ethnicity, give more detail.

For ethnicity, please let us know if you are Haitian, Vietnamese, Brazilian, etc. You can tell me in your own words and I will record your response.

If a client asks, “What is meant by Hispanic, Latino or Spanish?”

Explain: A person is Hispanic, Latino or Spanish if they or their family originally come from a country in Latin America or another Spanish-speaking country.

If a client asks, “What is race?” Use the following definition:

Race is the group or groups that you identify with as having similar physical characteristics or similar social and geographic origins. You can tell me more than one.

If the client cannot describe his or her race, give examples.

For race, please let us know if you are Asian, black, white, etc. You can tell me in your own words and I will record your response.

If the client responds, “I’m multiracial,” say:

We can record as many categories as you need to describe yourself. Please tell me all of your races.

Use the following questions to ask about primary language:

- What is the primary language spoken in your home?
- In what language do you prefer to discuss health-related concerns?
- In what language do you prefer to read health-related materials?
- Have you requested an interpreter if one is needed?

Tool 3.1: Explaining the Data Collection Process to Clients (cont.)

If the client thinks the answers are obvious, explain:

I understand that you may think that the answers are obvious. I have to ask every patient. It is really important that we record your response.

If the client refuses, reassure him or her and explain confidentiality and purpose:

I understand that these questions may be a little sensitive. We are required to ask all clients. This information will be kept private and will only be used to improve the care we provide to all clients.

If the client still refuses...

That is okay. You have the right to not answer these questions.

If the clients gets upset, say:

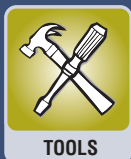
I will call my manager.

If the client wants more information:

Here is a pamphlet explaining more about why we are collecting this information and how it can be used to better meet the needs of communities we serve.

From: "Reporting Race, Ethnicity and Language: A Guide to Helping Patients," developed by Massachusetts hospital communities through the Massachusetts Hospital Association.

<http://www.mhalink.org>



Tool 3.2: MDPH Detailed Ethnicity Categories and Supplemental Code Set (December 2006)

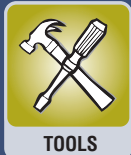
Ethnicity Categories	Subcategories and Supplemental Code Set
Cuban 2182-4	
Dominican 2184-0	
Mexican, Mexican American, Chicano 2148-5	Mexican American 2149-3, Mexicano 2150-1, Chicano 2151 – 9 , La Raza 2152-7, Mexican American Indian 2153-5
Puerto Rican 2180-8	
Salvadoran 2161-8	
Central American (Other) 2155-0	Costa Rican 2156-8, Nicaraguan 2159-2, Panamanian 2160-0, Central American Indian 2162-6, Belize
South American (Other) 2165-9	Argentinean 2166-7, Bolivian 2167-5, Chilean 2168-3 Ecuadorian 2170-9, Paraguayan 2171-7, Peruvian 2172-5, Uruguayan 2173-3, Venezuelan 2174-1, South American Indian 2175-8, Criollo 2176-6, Guyana

Tool 3.2: MDPH Detailed Ethnicity Categories and Supplemental Code Set (December 2006) (cont.)

African 2060-2	<p>Botswanan 2061-0, Ethiopian 2062-8, Liberia 2063-6, Namibian 2064-4, Nigerian 2065-1, Zairean 2066-9</p> <p>African also includes: Angola, Benin, Burkina Faso, Burundi, Cameroon, Central African Republic, Chad, Comoros, Congo, Cote d'Ivoire, Djibouti, Egypt, Equatorial Guinea, Eritrea, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Libya, Madagascar, Malawi, Mali, Mauritania, Mauritius, Morocco, Mozambique, Niger, Reunion, Rwanda, Sao Tome & Principe, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, Sudan, Swaziland, Tanzania, Togo, Tunisia, Uganda, Western Sahara, Zambia, and Zimbabwe</p>
African American 2058-6	
American AMERCN	
Asian 2028-9	<p>Bangladeshi 2030-5, Bhutanese 2031-3, Burmese 2032-1, Hmong 2037-0, Iwo Jiman 2048-7, Indonesian 2038-8</p> <p>Madagascar 2052-9, Malaysian 2042-0, Maldivian 2049-5, Nepalese 2050-3, Okinawan 2043-8, Pakistani 2044-6, Singaporean 2051-1, Sri Lankan 2045-3, Taiwanese 2035-4, Thai 2046-1</p>
Asian Indian 2029-7	
Brazilian BRAZIL	
Cambodian 2033-9	
Cape Verdean CVERDN	
Caribbean Island CARIB	<p>Barbadian 2068-5, Dominica Islander 2070-1, Jamaican 2072-7, Trinidadian 2074-3, Tobagoan 2073-5, West Indian 2075-0</p>
Chinese 2034-7	
Colombian 2169-1	

Tool 3.2: MDPH Detailed Ethnicity Categories and Supplemental Code Set (December 2006) (cont.)

European 2108-9	English 2110-5, French 2111-3, German 2112-1, Irish 2113-9, Italian 2114-7, Scottish 2116-2, Greek GRK, Spanish SPAN, Armenian 2109-7, Polish 2115-4 Albanian ALBA, Azerbaijan AZER, Belarus BELA, Bosnia and Herzegovina BOSHER, Bulgaria BULG, Croatia CRO, Czech Republic CZECH, Estonia EST, Georgia GEOR, Hungary HUNG, Latvia LAT, Lithuania LITH, Moldova MOLD, Macedonia MACD, Montenegro MONT, Romania ROM, Serbia SERB, Slovakia SLOVK, Slovenia SLOVE, and Ukraine UKR
Filipino 2036-2	
Guatemalan 2157-6	
Haitian 2071-9	
Honduran 2158-4	
Japanese 2039-6	
Korean 2040-4	
Laotian 2041-2	
Middle Eastern or North African 2118-8	Assyrian 2119-6, Egyptian 2120-4, Iranian 2121-2, Iraqi 2122-0, Lebanese 2123-8, Palestinian 2124-6, Syrian 2125-3, Afghanistani 2126-1, Israeli 2127-9 Middle Eastern also includes: Algerian, Jordan, Kuwait, Oman, Qatar, Saudi Arabia, Sudanese, United Arab Emirates, and Yemen
Portuguese PORTUG	Azorean, Canarian 2145-1
Russian RUSSIA	
Vietnamese 2047-9	
Other OTHER	
Unknown/ not specified UNKNOWN	



Tool 3.3: MDPH Race, Ethnicity and Language Preference Data Collection Instrument

Introduction

In order to guarantee that all clients receive the highest quality of care and to ensure the best services possible, we are collecting data on race and ethnicity. Could you please select the category or categories that best describes your background?

1. Are you Hispanic/Latino/Spanish?

- ☐ Yes ☐ No

2. What is your ethnicity? (You can specify one or more)

- | | |
|---|--|
| <input type="radio"/> African (specify_____) | <input type="radio"/> Haitian |
| <input type="radio"/> African-American | <input type="radio"/> Honduran |
| <input type="radio"/> American | <input type="radio"/> Japanese |
| <input type="radio"/> Asian Indian | <input type="radio"/> Korean |
| <input type="radio"/> Brazilian | <input type="radio"/> Laotian |
| <input type="radio"/> Cambodian | <input type="radio"/> Mexican, Mexican-American, Chicano |
| <input type="radio"/> Cape Verdean | <input type="radio"/> Middle Eastern (specify_____) |
| <input type="radio"/> Caribbean Islander (specify_____) | <input type="radio"/> Portuguese |
| <input type="radio"/> Chinese | <input type="radio"/> Puerto Rican |
| <input type="radio"/> Colombian | <input type="radio"/> Russian |
| <input type="radio"/> Cuban | <input type="radio"/> Salvadoran |
| <input type="radio"/> Dominican | <input type="radio"/> Vietnamese |
| <input type="radio"/> European | <input type="radio"/> Other (specify_____) |
| <input type="radio"/> Filipino | <input type="radio"/> Unknown/not specified |
| <input type="radio"/> Guatemalan | |

3. What is your race? (You can specify one or more)

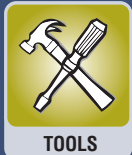
- ☐ American Indian/Alaska Native (specify tribal nation_____)
- ☐ Asian
- ☐ Black
- ☐ Native Hawaiian or other Pacific Islander (specify_____)
- ☐ White
- ☐ Other (specify_____)
- ☐ Unknown/not specified

4. In what language do you prefer to discuss health-related concerns?

- | | |
|---|--|
| <input type="radio"/> English | <input type="radio"/> Arabic |
| <input type="radio"/> Spanish | <input type="radio"/> Albanian |
| <input type="radio"/> Portuguese | <input type="radio"/> Chinese (specify dialect_____) |
| <input type="radio"/> Cape Verdean Creole | <input type="radio"/> Russian |
| <input type="radio"/> Haitian Creole | <input type="radio"/> Other (specify_____) |
| <input type="radio"/> Khmer | <input type="radio"/> Somali |
| <input type="radio"/> Vietnamese | |

5. In what language do you prefer to read health-related materials?

- | | |
|---|--|
| <input type="radio"/> English | <input type="radio"/> Arabic |
| <input type="radio"/> Spanish | <input type="radio"/> Albanian |
| <input type="radio"/> Portuguese | <input type="radio"/> Chinese (specify dialect_____) |
| <input type="radio"/> Cape Verdean Creole | <input type="radio"/> Russian |
| <input type="radio"/> Haitian Creole | <input type="radio"/> Other (specify_____) |
| <input type="radio"/> Khmer | <input type="radio"/> Somali |
| <input type="radio"/> Vietnamese | |



Tool 3.4: Race, Ethnicity and Language (REL) Data Sources

Massachusetts Sources for Race, Ethnicity and Language Data

- **Local hospital utilization data** of the primary/preferred languages of patients using the hospital.
- **Community input:** Input from a community advisory board, consultants and key informants from community-based organizations and/or community meetings.
- **Massachusetts Mutual Assistance Associations**, self-help agencies for newcomer communities, can provide useful information on the most recently arrived populations. A PDF directory of Massachusetts MAAs is available from <http://www.masslegalservices.org/docs/MutualAidAssociations.pdf>.
- General information from the **Massachusetts Immigrant and Refugee Advocacy Coalition (MIRA)**, a statewide coalition of grassroots immigrant organizations. <http://www.miracoalition.org>
- **“First Language is Not English” (FLNE) and Limited English Proficiency (LEP) surveys** of the public school system analyzed by the Department of Education and compiled by the MDPH Office for Refugee and Immigrant Health. <http://www.mass.gov/dph/omh.htm>
- Information collected by municipal **Boards of Health**.
- **Massachusetts Division of Medical Assistance** data on self-reported, preferred, spoken and written language preferences of MassHealth Benefit Request/Children’s Medical Security Plan applicants.
- **Massachusetts Community Health Information Profile (MassCHIP)** and a broader array of publications which include ethnic/racial group data and special reports on specific ethnic/racial groups. <http://www.masschip.state.ma.us>
- **MDPH’s Division of Research and Epidemiology** offers links to Massachusetts population health statistics including birth data, death data, Healthy People 2010 Leading Health Indicators, population information, race and ethnicity reports, Regional Health Status Indicators Reports, Smoking Reports and Women’s Health. <http://www.mass.gov/dph/resep>
- **U.S. Census data** of your service area. <http://quickfacts.census.gov/qfd/states/25000.html>

Tool 3.4: Race, Ethnicity and Language (REL) Data Sources (cont.)

U.S. Agencies Offering Relevant Race/Ethnicity Data

- U.S. Department of Housing and Urban Development (HUD)
<http://www.hud.gov>
- U.S. Department of Health and Human Services (HHS)
<http://www.hhs.gov>
- The Centers for Disease Control and Prevention (CDC)
<http://www.cdc.gov>
- National Institutes of Health (NIH)
<http://www.nih.gov>
- U.S. Department of Labor (DOL)
<http://www.dol.gov>
- Occupational Safety and Health Administration of DOL (OSHA):
<http://www.osha.gov>
- The U.S. Environmental Protection Agency (EPA)
<http://www.epa.gov>
- U.S. Department of Education (DOE)
<http://www.ed.gov>
- HHS Health Resources and Services Administration Bureau of Primary Health Care
<http://datawarehouse.hrsa.gov>

Other Sources of Immigration and Language Data

Modern Language Association (MLA) Language Map

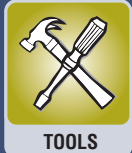
<http://www.mla.org>

Displays the locations and numbers of speakers of the thirty languages most commonly spoken in the U.S.

Migration Information Source

<http://www.migrationinformation.org>

Global and U.S. data on migration, country and population profiles.



Tool 3.5: Low-Cost Data Collection Tools

Chronic Disease Electronic Management User Network (CDEMS)

CDEMS is a software application developed by the Washington State Diabetes Prevention and Control Program in 2002. This Microsoft Access database application is designed to help medical providers and managers in tracking the care of patients with chronic health conditions. The application allows users to define tracking measures for any chronic health condition. The CDEMS resource offers links to resources including a data entry guide, a reports guide and an electronic lab interface guide.

Epi Info

<http://www.cdc.gov/epiinfo>

With Epi Info and a personal computer, public health and medical professionals can rapidly develop a questionnaire or form, customize the data entry process, and enter and analyze data. Epidemiologic statistics, tables, graphs and maps are produced with simple commands such as READ, FREQ, LIST, TABLES, GRAPH and MAP.

Massachusetts Hospital Association Training Resources

<http://www.mhalink.org/public/news/2006/2006-11-09.cfm>

The Massachusetts Hospital Association offers a number of adaptable resources to streamline race, ethnicity and language data collection, including Frequently Asked Questions, scripts, and strategies for updating data collection systems.

Patient Electronic Care System (PECS)

Bureau of Primary Health Care

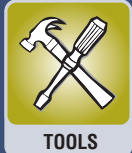
http://www.cpc.org/healthcollabs/documents/PECS_Info_Packet.pdf

The PECS is a software program specifically aimed at supporting the adoption of the Care Model in the care of patients with diabetes, cardiovascular disease, asthma, depression, cancer and preventive service needs. The program was designed as an easy-to-use, simple tool for information entry, retrieval and review.

Survey Monkey

<http://www.surveymonkey.com>

Survey Monkey is online survey software designed to enable users to create professional online surveys quickly and easily. The software includes some free features for surveys with up to 100 responses and is also available for a monthly or annual fee.



Tool 3.6: Resources

Data Collection Resources

Massachusetts Hospital Association

<http://www.mhalink.org/public/news/2006/2006-11-09.cfm>

The Massachusetts Hospital Association has developed valuable guidance for the collection of race, ethnicity and language data, including Frequently Asked Questions (FAQs), scripts, and strategies for updating information systems.

Data Collection Guidelines

Boston Public Health Commission

<http://www.bphc.org/bphc/pdfs/datacollectionguidelines.pdf>

The Boston Public Health Commission issued a set of helpful guidelines on collecting race, ethnicity and language data.

Disparities Solutions Center

Massachusetts General Hospital

<http://www.mghdisparitiessolutions.org>

The Disparities Solutions Center at Massachusetts General Hospital site offers a number of data collection resources, including:

- *Getting Started: Building a Foundation to Address Disparities through Data Collection.* A Web seminar answering questions about practical aspects of data collection.
- *Getting it Right: Navigating the Complexities of Collecting Race/Ethnicity Data.* A panel of experts answers questions about moving forward with data and the obstacles, barriers and complexities you may encounter, including legal concerns and geocoding.
- *Creating Equity Reports: A Guide for Hospitals.* A how-to guide with practical information on collecting and using data to develop an equity report.

HRET Disparities Toolkit: A Toolkit for Collecting Race, Ethnicity and Primary Language Information from Patients

The Health Research and Educational Trust

<http://www.hretdisparities.org>

A user-friendly, Web-based tool developed by HRET and the American Hospital Association. Provides information and resources for collecting race, ethnicity, and primary language data from clients. Free access with registration.

Policy Brief: The Legality of Collecting and Disclosing Patient Race and Ethnicity Data

George Washington University School of Public Health and Health Services

http://www.healthinfolaw.org/uploads/racial_and_ethnic_data.pdf

An excellent, detailed report explaining how race and ethnicity data collection is supported by federal civil rights and other laws.

Tool 3.6: Resources for More Information (cont.)

Racial, Ethnic and Primary Language Data Collection: An Assessment of Federal, Policies, Practices and Perceptions, Vol. 2

National Health Law Program

<http://www.healthlaw.org/library/item.72789>

A comprehensive overview of federal policies and guidelines for race, ethnicity and language data collection.

Further Reading

Lurie, N and A. Fremont. *Looking forward: cross-cutting issues in the collection and use of racial/ethnic data*. Health Serv Res. 41 (4 Pt 1) (2006):1519-33.

Hasnain-Wynia, R, and D.W. Baker. *Obtaining data on patient race, ethnicity, and primary language in health care organizations: current challenges and proposed solutions*. Health Serv Res. 41(4 Pt 1) (2006):1501-18.

Moy E, I.E. Arispe, J.S. Holmes, and R.M. Andrews. *Preparing the national healthcare disparities report: gaps in data for assessing racial, ethnic, and socioeconomic disparities in health care*. Med Care. 43 (3 Suppl) 2005:19-16.

Past issues of the following two journals have addressed racial and ethnic disparities and race/ethnicity data:

Medical Care (Vol 44, No 11, Suppl 3, November 2006)

The Journal of Law, Medicine & Ethics (Vol 34, No 3, Fall 2006)